UNITED
NATIONS

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Economic and Social
Council

Distr.
GENERAL

E/CN.4/Sub.2/AC.4/1998/4/Add.1
15 June 1998

Original: ENGLISH

COMMISSION ON HUMAN RIGHTS

Sub-Commission on Prevention of
Discrimination and Protection
of Minorities
Working Group on Indigenous Populations
Sixteenth session
27 - 31 July 1998
Item 6 of the provisional agenda

INDIGENOUS PEOPLES AND HEALTH: FOLLOW UP AND RECENT DEVELOPMENTS

Note by the secretariat

Information received from indigenous organizations

1. In resolution 1982/34 of 7 May 1982, the Economic and Social Council authorized the Sub-Commission on Prevention of Discrimination and Protection of Minorities to establish annually a working group on indigenous populations to review developments pertaining to the promotion and protection of the human rights and fundamental freedoms of indigenous populations, together with information requested annually by the Secretary-General, and to give special attention to the evolution of standards concerning the rights of indigenous populations.

2. The Sub-Commission, in its resolution 1997/14 of 22 August 1997, requested the Secretary-General to transmit the report of the Working Group to intergovernmental, indigenous and non-governmental organizations and to invite them to provide information. The Commission on Human Rights, in its resolution 1998/13 of 9 April 1998, urged the Working Group to continue its comprehensive review of developments. The present document contains information in relation to item 6 of the provisional agenda.

INTERNATIONAL INDIAN TREATY COUNCIL

[Original: English]
[4 June 1998]

The collection, study and commercialization of human genomes and their impacts on the rights of indigenous peoples

Introduction

1. In the latter part of the twentieth century, indigenous peoples are threatened by bio-technology as the newest form of racism, colonialism, and economic exploitation. With the combined technological advances in molecular biology and "rapid sequence reading" by computers, scientists are able to identify unique genetic data in human DNA from the collection of hair, blood, tissue, mucous membrane and saliva samples. Cells and genetic materials generated from these samples are used in scientific experimentation as well as in obtaining commercial patents of living cell-lines.

2. Genetic samples are "immortalized" or genetically altered to live virtually forever, and stored in commercial and government gene banks around the world, providing a perpetual source of cell-lines and genomes that can be sold for genetic research, studies, and commercial product development.

3. Identified as special targets for such collections and studies, indigenous peoples have seen the need to engage international bodies, governments and the scientific community in an attempt to establish international standards respectful of their sacred genetic heritage, which represents an unbroken chain of life linking us with our ancestors and our descendants. The viability of this ongoing physical and spiritual connection down through the generations is essential to the survival of indigenous people.

The Human Genome Diversity Project (HGDP)

4. Beginning in 1991, a human population genetics research programme called the Human Genome Diversity Project (HGDP) was created by geneticists and molecular biologists, many of whom are financed by government research grants, to conduct a worldwide systematic study of the genetic diversity of human populations. The HGDP, by promoting collection, storage and study of the genetic materials of human population groups rather than of individuals, opened the door for potential widespread use and abuse of collective human genetic materials for scientific, commercial and military purposes, as well as for other similar projects currently under way or under development.

5. Because the more isolated, homogeneous, so-called "pure" human groups, referred to as "Isolates of Historic Interest", were identified as the most informative for human population genetics research, over 700 distinct indigenous peoples were targeted by the HGDP as subjects for investigation through collection and study of their DNA materials. Indigenous peoples considered to be under threat of extinction or assimilation were also targeted, purportedly to preserve their genetic identity as the common property of science and humanity. Science would be used to preserve the

genetic heritage of indigenous peoples virtually forever in genetic data banks, but apparently not to safeguard their existence as living, distinct peoples occupying (and protecting) their traditional lands.

6. The HGDP and other similar projects never have responded adequately to the myriad fundamental ethical questions concerning their proposals. These include the disturbing overtones of racism, the dissociation of control and decision-making regarding the use of collected genetic materials, the targeting of isolated communities, the basic issue of informed consent as applied to the collective nature of genetic materials, as well as the advanced technologies which are imposed on such collected genomes. These include genetic engineering, cloning, germ-line (reproductive cell) gene transfers, transgenic (cross-species) genome splicing and other experimental procedures under development.

7. In 1994, the Human Genome Organization (HUGO), an international coordinating body of scientists and others interested in genetic research, agreed to oversee the progress of the HGDP. HUGO is a multinational, multi-billion-dollar initiative by scientists, which seeks to sequence the DNA in the entire human genome structure. While HUGO intends to map and sequence the entire human genome, the HGDP seeks to map the variance, that is, the genetic differences of groups that differ from the monotype Genome that will be identified by the HUGO effort. HUGO also plays a coordinating role for the Human Genome Project (HGP) which comprises numerous similar projects funded by individual countries.

8. Although the HGDP has no substantial funding and remains largely in the planning stage, it actively seeks endorsements and support for its proposal. In 1995, the HGDP approached the UNESCO International Bioethics Committee (IBC) to seek international support and endorsement. UNESCO refused to endorse it or any other project in this area in order to maintain its credibility and neutrality. Conversely, the IBC is considering creating an International Oversight Committee on Population Genetics, which will include participation of indigenous representatives.

9. On 21 October 1997 the United States National Research Council (NRC) also apparently refused the HGDP's petition for endorsement, citing the need to look further into both scientific merits as well as policy and ethical issues. However, and somewhat contradictorily, the NRC recommended that the HGDP "focus their financial support, at least initially, on projects originating in the United States and expand their support to the international scene only after the US activities are successfully launched".

10. Recently, the HGDP has been meeting with indigenous peoples from the United States and Canada to exchange ideas and increase understanding about the HGDP. As part of this process, the HGDP is soliciting comments on a document for collecting DNA samples entitled "Proposed Model Ethical Protocol" (MEP) which also addresses the ethical and legal issues of population genetics. Yet there remains a sizable gap, in both interests and world view, between those populations targeted to be sampled and the unspecified goals of the funders of the research (corporations and Governments). Informed consent issues, in particular, are still not adequately addressed.

Indigenous world view and the human genome

11. In numerous declarations and resolutions throughout the world in recent years, thousands of indigenous peoples, organizations, coalitions, tribal groups and representatives have consistently expressed their vehement opposition to the HGDP specifically, and in general to the harvesting, patenting and study without fully informed consent of their genetic heritage by multinational corporations as well as scientists and government institutions. In their opposition to human population genetics research projects targeting their communities, indigenous peoples uphold the traditional perspective that the spiritual well-being of our peoples and the survival of our future generations is based upon a direct and unbreakable link from our ancestors. The human genome (the 23 pairs of chromosomes in a human cell) determines the collective physical identity of distinct peoples. As such, it constitutes the common "property" of a people in the most basic and fundamental sense. A people's genetic material collectively belongs not only to the living community of today, but to the ancestors from which they were passed down and the children who will one day inherit them. The unique genetic imprint of a people is also inextricably tied to the water, land, plants and animals with which that people shares its ecosystem and upon which it depends for its physical subsistence and spiritual survival. This basic component of human life, the source of a people's collective identity and genetic heritage, in the view of many indigenous peoples has its own spirit. It cannot be sold, altered or manipulated without potentially causing grave harm to the entire community, now and in the future. This perspective is a fundamental aspect of the religious and spiritual world view, reflecting the sacredness and interrelationship of all life, which underlies the adamant position taken on this issue by indigenous peoples.

12. Indigenous organizations and peoples from all regions of the world have joined in the call for an international moratorium on the patenting of life-forms, including human genetic materials, until the grave concerns regarding the spiritual, social, political, legal health and economic impacts on their peoples can be adequately addressed.

Commodification and patenting of indigenous people's DNA

13. Under international "intellectual property" and patenting laws, an "immortalized" or slightly altered human cell-line can be owned by an "inventor" or a biomedical company. Patenting has become an issue in population genetics research primarily in relation to the patenting of products derived from the genetic material of indigenous peoples.

14. On this matter there are several general positions taken by indigenous peoples. One is based on the opposition to any patenting of "life", which includes microbial, plant, animal and human life. Another position is that patenting should be opposed on the grounds that peoples from whom genetic material is taken are not guaranteed any financial or health benefits from it, and in fact have no legally protected determination over its eventual use.

15. Where patents originally were restricted to the protection of industrial processes and applications, they are now applied to microorganisms, animals, the species of an entire food crop, as well as the cell-lines of human beings.

Under United States legal doctrine, the "modification" of genetic material can be interpreted as "creation" or "invention", allowing the patenting of altered biological material, including cell-lines "shuffled" from human genes. A landmark case in point is Moore v. Regents of the University of California (1990), patent No. 4,438,032, involving the cell-line of Mr. John Moore, a non-indigenous person, which had been patented without his knowledge or informed consent. The cell-line has a potential market value of US$ 3 billion. The California State Supreme Court decided that Mr. Moore had no ownership rights to his own cells once they were removed from his body.

16. Three significant cases specifically involving indigenous peoples and the patenting of their cell-lines in the United States included a young Guaymi woman from Panama, an indigenous man from the Solomon Islands, and a Hagahai person from Papua New Guinea. In all three instances, due in large part to international public outcry, the patents were finally either dropped or withdrawn. A fourth and pending case involves Colombian indigenous peoples who are fighting to regain control of well over 1,000 human tissue samples taken by genetic researchers and exported to the United States of America, by the National Institute of Health (NIH) without their consent. Various other patents are also pending.

17. The commercial usage of the genetic material of the Pima Indians of the south-western United States is a particularly glaring example of what can happen once tissue samples leave the human body. The Pimas, who suffer from disproportionate levels of diabetes, agreed to participate in a study to determine if the disease had a genetic basis and, ostensibly, to develop cures from which the community could benefit. But after more than 30 years of sample collection and analysis by a broad range of institutions and scientists, no genetic cause for diabetes has been found. Pima Indian genetic materials and cell-lines, now "immortalized", are widely disseminated by genetic data banks and sold as a commodity to further enrich the multi-million-dollar bio-technology industry. This commercialization and sale, as a "secondary" use of tissues and cells originally collected for "humanitarian" health purposes, is an example of what indigenous peoples refer to as "biological piracy", the outright theft of resources generated by the commodification of living tissues without permission or compensation.

18. On 10 May 1998 the Institute for Genomic Sciences based in Rochville, Maryland (United States of America) and the Applied Biosystems division of Perkin-Elmer Corporation of Norwalk, Connecticut (United States of America) joined and proposed a plan to decipher the entire DNA of humans within three years. They contend that the private sector will be able to accomplish this goal much faster and cheaper than the federal Government agencies involved in the same research. In light of this development, the NIH will try to convince the United States Government to continue funding their genome project and will switch their focus from determining the DNA sequence to "interpreting" it.

19. International trade organizations such as the World Trade Organization (WTO) and the World Intellectual Property Organization (WIPO) have no responsibility or legal obligation for the protection of indigenous people's traditional knowledge or innovations, or for taking into account their concerns regarding the patenting of the human cell-lines of their peoples.

20. WIPO stipulates that "intellectual property" refers to property generated by intellectual creations, particularly technological inventions and literary and artistic works. "Property" means that protected inventions and works under copyright protection can be used only with the consent of the inventor, author or other "owner" of the rights. In 1997 WIPO established the "Global Intellectual Property Issues Division" (GIPID) to examine and explore newly emerging intellectual property issues, including concerns raised by indigenous peoples. In its 1998/99 workplan, WIPO-GIPID have called for a round table on indigenous intellectual property to be held in Geneva in July 1998. The discussion will focus on biodiversity and biotechnology.

21. Indigenous peoples intend to seek clarification from WTO and WIPO regarding the distinction in patent law between inventions, which may be patented, and discoveries, which cannot, and whether the results of human genetic research can therefore be patented by commercial interests.

Informed consent

22. The Universal Declaration of Human Rights affirms the rights to be protected from being arbitrarily deprived of property, to the dignity, worth and security of the person, to privacy and to participate freely in the cultural life of the community, along with other rights which are embodied in the principles of informed consent. Likewise, the International Covenants on Civil and Political Rights and on Economic, Social and Cultural Rights both stipulate that all peoples, by virtue of their right to self determination, freely determine their economic, social and cultural development. These international standards reflect a recognition of the rights encompassed in and protected by the principle of informed consent as applied to the individual, as well as collectively to all peoples.

23. The application of the principle of informed consent as applied to the collection and use of human genetic materials is necessarily complex and far reaching. The collective significance of the human genome to entire communities and peoples, the intimidating nature of the advanced bio-technologies used to study and manipulate these genetic materials, the legal impacts of international patenting laws and trade agreements, and the widespread international proliferation and secondary usage of cell-lines all greatly impact the informed consent considerations as applied to this area.

24. It is important to note that after the Second World War, the Nüremberg Charter mandated that no medical experiments could be performed without the informed consent of the patient. That treaty, of which the United States of America was a leading proponent, does not allow for any exceptions to the requirements of informed consent.

25. Past abuses of the informed consent principle by government, military and medical experimentation conducted upon their communities have not been forgotten or forgiven by the affected indigenous peoples, many of whom are suffering long-term health effects to this day. Such communities therefore view with suspicion the ever-more-sophisticated bio-medical technologies which have proliferated in recent years. For example, members of several distinct Alaskan indigenous communities, including pregnant mothers and boarding-school children, were targets of government and military medical experimentation in

the 1950s which exposed them to radioactive pills, liquids and injections without their knowledge or consent, in order to test if these peoples possessed an inborn resistance to the cold. This study is similar in intent to many of the genetic-based studies currently proposed and under way which attempt to identify the unique physical attributes of targeted peoples. The result is a deep, and arguably justified, apprehension regarding the possibility of being used as "guinea pigs" again by government scientists now armed with the ability to isolate and target specific human genes.

26. Today, sources of human cells and genetic materials being studied and sold by the bio-technology industry include tissues obtained from medical studies (such as in the case of the Pimas), surgical procedures (including infant circumcisions and abortions), autopsies, and even ancestral remains unearthed by archeologists. It is clear that informed consent is not a primary concern for those doing genetic "harvesting" under these circumstances.

International standards and action by United Nations bodies

27. The first official recognition by the United Nations system of the overall impact of ethnocide against indigenous peoples was a result of a conference sponsored by UNESCO and held in San José, Costa Rica, in 1981. The Declaration of San José which resulted was a statement of principles reaffirming the right of indigenous peoples to preserve and develop their own cultures and diverse cultural heritage.

28. The study conducted by the United Nations entitled "Study on the protection of the cultural and intellectual property of indigenous peoples", by Erica-Irene Daes, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities and Chairperson of the Working Group on Indigenous Populations (E/CN.4/Sub.2/1993/28) raised many important concerns and made many recommendations for standard-setting, addressing the cultural, spiritual and scientific traditions that are directly applicable to this issue.

29. Another document of value to this discussion was the working paper prepared by Mr. Osman El-Hajjé in conformity with Sub-Commission decision 1996/110, "Potentially adverse consequences of scientific progress and its applications for the integrity, dignity and human rights of the individual" (E/CN.4/Sub.2/1997/34). In the working paper's conclusions and recommendations, Mr. El-Hajjé called for the drafting of universal legislation which would safeguard cultural and religious specificities while ensuring the protection of human rights and dignity. Another recommendation was the establishment of an international committee on ethics which would submit an annual report on the state of science and technology to the General Assembly.

30. The Convention on Biological Diversity does not distinguish human cells or DNA from plant and animal tissues, cells, seeds and DNA, which are considered part of "biological diversity". The CBD also omits any recognition of indigenous peoples' rights to determine freely the use of their traditional knowledge or biological resources, or to the application of informed consent procedures regarding the commercialization of resources removed from their

traditional lands. Using wording currently under intense scrutiny by indigenous peoples, the CBD recognizes only their right to share in the economic benefits derived from these resources.

31. The United Nations has produced only a few documents directly addressing fundamental questions on human rights and the discriminatory impacts of human genetic harvesting and experimentation. Beginning at its fifty-first session the Commission on Human Rights, in resolution 1995/82, invited Governments, specialized agencies and other organizations of the United Nations system to inform the Secretary-General of activities being carried out to ensure that the life sciences developed in a manner respectful of human rights and beneficial to humanity as a whole. A report (E/CN/4/1995/74) analysed measures taken by the United Nations in this field. The most recent report of the Secretary-General on human rights and bioethics (E/CN.4/1997/66), submitted to the fifty-third session of the Commission, begins to shed light on the extent of the legal, social, economic and ethnical problems of concern to Member States, specialized agencies, religious denominations and NGOs.

32. Only recently have States begun to draft national legislation relating to medical research and experiments on human subjects or to establish national consultative bodies to address this growing bio-medical enterprise and its potential for misuse.

33. In a landmark action, the Sub-Commission at its forty-ninth session, responding to concerns of indigenous peoples, included in that and previous years' reports of the Working Group, adopted resolution 1997/15 entitled "International Decade of the World's Indigenous People" in which it made specific reference for the first time to the rapid rise of biotechnology and its affect upon indigenous peoples. This resolution of the Sub-Commission represented a major breakthrough in its explicit recognition of indigenous peoples as a vulnerable group susceptible to being singled out for human gene research and human gene patenting by the biotechnology industry, and in bringing this issue into focus as a matter of potential discrimination and human rights abuses against indigenous peoples.

The UNESCO Declaration

34. On 11 November 1997 the Universal Declaration on the Human Genome and Human Rights was adopted unanimously by the twenty-ninth General Conference of UNESCO, becoming the first universal instrument in the field of biology. It addresses the question of human dignity and the problems posed by advances in science. On several occasions Indigenous delegates to the UNESCO IBC in the past have called for support for the Draft United Nations declaration on the rights of indigenous peoples, and particularly to consider the adoption of article 29 as the best mechanism developed to date for the protection of indigenous peoples' rights in this area. The next meeting of the UNESCO IBC will be held in Cape Town, South Africa, in October 1998. Indigenous peoples can once again request that the article 29 of the draft declaration be considered for inclusion among the 25 articles of the Universal Declaration. Also, and more specifically, the question of "collective rights", particularly with reference to human population genetics, can be raised again for the IBC's consideration.

Conclusions and recommendations:

35. Indigenous peoples participating at the present session of the Working Group are able to present many specific cases as well as diverse aspects of this issue which were not able to be covered in this short discussion paper. They will also be able to make recommendations, in keeping with the mandate of the Working Group to review developments and develop new standards, arising from the concerns of their communities and leadership on this issue.

36. IITC would like to offer two recommendations at this time, to be considered for discussion during the current session of the Working Group:

(a) Endorsement by the Working Group of a call for an international moratorium on the collection of indigenous peoples' tissues, DNA, cells and genomes until the full political, legal, social, economic and cultural implications of such activities are addressed by all participants and involved parties, with the full participation of indigenous peoples;

(b) Initiation by the Working Group of a process for the development, in collaboration with indigenous peoples, of effective international standards addressing the collection, use, study and sale of the genetic materials of indigenous peoples, prioritizing respect for indigenous peoples' religions and cultures, recognition of their collective rights to self-determination and traditional decision-making processes, safeguarding of human rights, delineation of culturally appropriate informed consent procedures, and implementation of mechanisms to monitor institutions, corporations, governmental agencies, trade bodies, scientific laboratories and patent offices.

Appendix V

DECLARATIONS AND RESOLUTIONS ADOPTED BY INDIGENOUS PEOPLES EXPRESSING OPPOSITION TO THE HGDP, PATENTING OF GENOMES AND/OR BIO-PIRACY (PARTIAL LIST)

1. Karioca Declaration (June 1992, Brazil)

2. The Mataatua Declaration (June 1993, Aoteroa)

3. The United Nations Working Group on Indigenous Populations, adoption of article 29, Draft United Nations declaration of the rights of indigenous peoples, (July 1993 and 1994)

4. Maori Congress (1993, Aotearoa)

5. World Congress of Indigenous Peoples (1993)

6. National Congress of American Indians (1993, United States of America)

7. Central Australian Aboriginal Congress Position Paper on the HGDP "Vampire" Project (November 1993)

8. Maori Congress Indigenous Peoples Roundtable (June 1994, Aoteroa)

9. Guaymi General Congress (1994, Panama)

10. Geneva Workshop on Intellectual Property Rights (August 1994)

11. Latin and South American Consultation on Indigenous Peoples, Santo Cruz De La Sierra (September 1994, Bolivia)

12. Asian Consultation on the Protection and Conservation of Indigenous Peoples' Knowledge (February 1995, Malaysia)

13. Declaration of Indigenous Organizations of the Western Hemisphere (February 1995, Phoenix, Arizona, United States of America)

14. Pan-American Health Organization (April 1995)

15. Pacific Consultation on the Protection and Conservation of Indigenous Peoples' Knowledge, Suva Statement (May 1995)

16. The "Heart of the Peoples" Declaration, from the North American Indigenous Peoples' Summit on Biological Diversity and Biological Ethics (August 1997, Fort Belnap, Montana, United States of America)

17. Kuna Yala Declaration on the Human Genome Diversity Projects (November 1997, Kuna Yala, Panama)